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The importance of patient-centred care: the experience of individuals with colorectal cancer.

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Introduction

An emerging emphasis on the importance of health care that is organised to meet the needs of the patient as opposed to the needs of health care professionals (HCPs) has led to the development of patient centred care (PCC). PCC is a widely used phrase, but is not well defined (1). One frequently cited reference is provided by the Institute of Medicine (IOM) who defined PCC as *‘providing care that is respectful of, and responsive to individual patient preferences, needs and values and ensuring that patient values guide all clinical decisions’* (2). In their report, the IOM reiterated the six components of PCC as suggested by Gerteis et al. (3) which demonstrate the multidimensional nature of PCC (see Box 1).

**Box 1: The six components of PCC as recommended by the IOM (2001)
(from Gerteis et al., 1993)**

1. Compassion, empathy and responsiveness to the needs, values and expressed preferences.
2. Co-ordination and integration.
3. Information, communication and education.
4. Physical comfort.
5. Emotional support, relieving fear and anxiety.
6. Involvement of family and friends.

Many government documents have emphasised the importance of PCC. Improving patient experience was a prominent theme in Lord Darzi’s NHS Next Stage Review (4). Lord Darzi recommended that health care should be personalised and that patients should be given more control over their health care. He concluded that information should be more responsive to personal needs, as should the ‘system’ itself (4). This report led to the development of the first NHS Constitution. The fourth principal of the constitution states that NHS services must reflect the needs and preferences of patients, their families and carers (5).

PCC has become a key determinate of good quality health care. In order to deliver high quality care, HCPs should endeavour to empower patients, encouraging them to establish their own health care needs and adopt a dynamic role in their health care.

Establishing and maintaining a person-centred approach can be complex and challenging. One of the biggest challenges to PCC is that it perpetuates the doctor's role as the 'expert' (6). The doctor gives information, provides education, ensures services are appropriate for the individual and seeks input from the patient which may reinforce a patient's passive reliance on their doctor (6).

This report provides an illustration of some considerations for PCC for individuals with colorectal cancer (CRC). It examines circumstances of high-quality and insufficient PCC, highlighting the challenges of implementing successful PCC. This is achieved through a discussion of relevant findings from a qualitative study which examined the experience of men and women with CRC.

Background to study

As part of a larger investigation into the health of men with cancer, a qualitative study was conducted examining the experience of men and women with CRC. The overall aim of the study was to explore the experience and coping behaviour of men and women with CRC over an 18-month period post-diagnosis. The relevant data on patient experience are presented in this report.

Colorectal Cancer

CRC is the third most common cancer in the United Kingdom and North America (7,8). The occurrence of the disease is related to age, with over 80 percent of first diagnoses occurring in the over sixties. Until the age of fifty, there is no gender difference in incidence and mortality rates, but in later life the mortality rate in males is much greater than that in females (7,8). The main treatment option for CRC is surgery, which may result in the formation of a colostomy or ileostomy. Many individuals also have radiotherapy and/or chemotherapy. Significant improvements in survival have been noted for CRC over the last 30 years (9), with approximately fifty percent of people diagnosed with bowel cancer surviving for at least five years after diagnosis (8). Individuals with a history of CRC are the second largest group, after breast cancer, of European cancer survivors (10).

The study

A longitudinal qualitative study was conducted involving individuals with CRC (n = 38; 24 male). Data were generated using semi-structured interviews at four time points. Interviews were conducted after surgery, on completion of chemotherapy, and six months and twelve months post chemotherapy. Those individuals who did not receive chemotherapy were interviewed at six monthly intervals post-surgery. The sample consisted individuals with CRC, who were over 18 years of age, were aware of their diagnosis and able to communicate about their experience. Recruitment continued until data saturation had been reached. Data were analysed in accordance with Miles and Huberman (11) techniques of labelling, coding, categorising and theme development. Data collection and analysis were undertaken concurrently.

The findings relevant to PCC have been grouped under two headings: information seeking and social support. Information seeking in relation to diagnosis and treatment has been described as health information seeking behaviour (HISB) (12). Social support refers to the support received (e.g. informational or emotional) or the sources of support (e.g. family and friends, or the medical profession) (13). Social support can be divided into two categories; practical support ('caring for') and emotional support ('caring about') (14). Findings in relation to respondents' preferences for HISB, sources of social support and circumstances when respondents felt support were lacking are presented.

Findings relevant to PCC

Information seeking

Overall there appeared to be two loosely identified groups with regards to information seeking: those who wanted a significant amount of information from a variety of sources (active information seekers), and those who were satisfied with the information they received from their doctor (passive recipients).

Information at diagnosis and during treatment

Active information seekers

These participants were pro-active in gaining information; asking questions of their doctor, seeking out relevant information on the Internet and talking to peers. For some it appeared they wanted the information to facilitate informed decision making.

They have given you the choice as well, very clearly, having explained to you that in their experience, the best course of action, giving you a very clear choice that you can go with it or walk out the door, it is up to you.' (001)

'I want to know exactly where I am at each stage and all the information because I want to make informed choices' (019)

A common feature of these individuals was a personal CRC knowledge base. This arose either from their profession, a family member, or as a result of them conducting their own search upon diagnosis. As a result of this they felt empowered to ask questions of the doctor.

'.....because you had done your own research in advance, you could have a conversation with them at my level as opposed to the level they maybe use between themselves.' (001)

These individuals appeared to experience satisfactory PCC. In their opinion, they received an adequate amount of information from the medical profession and when they asked questions, they were well received.

'.....like I went down sometimes with a list of questions, daft questions and no, they always, always treated it as.....this is great, this is what we want to see.' (008).

'At no stage was I left in the dark and they always gave me as much information as I needed....' (001)

This group still viewed the doctor as the 'expert'; they placed emphasis on his opinion, and wanted information that was specific to them.

'You have to realise that every individual is an individual and the answer that I get is based on the consultant's experience.....and I think that's what you have to trust in.' (023)

However, many in this group experienced poor PCC in relation to diet. There was a sense of disappointment that dietary advice was not routinely offered. Great importance was placed on receiving information from someone who was seen as an 'expert' in the area.

'somebody coming in like a dietician who would give you some idea, even when you left hospital, what you should be eating. Again, I don't think a doctor knows all that much.' (012)

Many of these patients were now living with a stoma. Patients expressed dissatisfaction with the information received at the time of surgery. For example, one man described how he felt

he was given information on the stoma too close to the operation. He did not feel he had been involved in the decision on stoma placement.

'the first time I saw the stoma nurse was the day prior to surgery. I don't think that gave me enough time to take it all in to be honest. It's the sort of thing you need to talk about becauseit has to suit your body and your life style.' (052)

In the period between surgery and chemotherapy, a number of respondents in this group were disappointed in the amount of information they were given in relation to chemotherapy. This was an anxious time which was worsened by the lack of information.

'There needs to be a preliminary (chemotherapy) meeting of some sort or some better knowledge given to the patient and their family much earlier.....there is absolutely no information at all.' (021)

Some thought they were 'cured' following their surgery and did not realise they needed to have chemotherapy treatment. Subsequently at their first oncology appointment, they described how it was like being told they had cancer all over again, and they went through another stressful process.

'Well he started to talk about chemotherapy but to tell the truth it scared me because I thought I was just more or less going up for a (check up).....Then he started to talk about 26 weeks and getting chemotherapy and things like that. Here's me, I thought the operation was...a success.' (026)

Passive recipients

This group described how they adopted a passive role in information gathering and relied on the doctor providing them with the necessary detail.

'Yes just what the doctors said. I never researched nothing into it at all, just what the doctors told me.' (045)

Many in this group found retention of verbal information difficult; they found leaflets and diagrams useful as they could review the information in their own time. They had a tendency to gather information retrospectively, as opposed to the 'active information seekers' who consistently sought information during and following their diagnosis and treatment.

'i think you need the information to go back on. I think it helps if you can go back on it and see what they actually did. Sometimes you are told things but are not listening properly.....' (002)

Superficially it appeared that these individuals experienced good PCC. They did see the need to do their own search into CRC, and were satisfied with the level of information they received from the medical profession. However, unlike the 'active information seekers', this group had scant knowledge of CRC and were therefore not empowered and so unable to be part of the decisions relating to their cancer. The control lay with the medical profession; they informed the patients what they believed the individual with CRC needed to know. The individuals in this group had limited insights into their information needs. There was evidence in the narratives that these individuals would have asked more questions, if they had had enough knowledge to know what to ask.

'When I went to see the doctor he asked me if I had read the information and I hadn't. I still hadn't read it. So I couldn't even ask questions about it.....' (002)

'the doctors and nurses told me everything I needed to know and I didn't really have any questions because I didn't really know what to ask them.....I think I could have asked more questions about it but I didn't know what sort of questions to ask.....' (030)

Some respondents were highly satisfied with limited information on their diagnosis and treatment. This minimal information provided by the medical profession met their PCC needs. To illustrate, when asked about information seeking from other sources (not the medical profession), an individual responded:

'Well in relation to the cancer, no.....To be quite frank with you, I just said no look, you are the experts and I'm putting myself in your hands as such and I didn't have any doubt about that.' (023)

Within the passive information seekers, there existed some individuals who appeared to completely avoid some information, particularly in relation to chemotherapy treatment. They reported feelings of anger towards the medical profession for giving them what they deemed to be un-necessary information. However, contradiction within the narratives revealed that they would have welcomed more detailed information but appeared unaware of that need.

'I just don't want to know that I'm going to have pain or to be sick. I just want everything over and done with.....I know that you are better knowing at the end of the day because if something did happen.....say you took mouth ulcers or something did happen, you would probably be worrying more because you would be saying, well why am I taking this?' (010)

Information after treatment

Information provided to participants after treatment was an area of concern for PCC. Whether they were classed as active information seekers or passive recipients, participants identified a need for more information on follow-up appointments and scans. This increased anxiety in a number of individuals who placed great importance on their scans to detect any signs of a recurrence.

'It's the lack of information.....You are left in limbo..... Why don't they send me for a scan or whatever?.....At least I would know they are going to come to me instead of me hanging about and you don't know whether it's cured or in remission or still there.' (044)

Social support

Preferences for sources of social support

Narratives suggested that social support was provided by a number of sources including the medical profession, friends and relatives, other individuals with cancer, and religious communities. Different sources provided different types of support. The medical profession provided the participants with informational support, as did other patients. Family and friends appeared to be the main sources of emotional and instrumental support. However, some individuals seemed to express resentment towards this support and their loss of independence.

'Having to rely on other people I don't like. I've never had to rely on others so I don't like that. I don't like not being able to do things.' (008)

One man discussed how he did not tell friends that he had been diagnosed with CRC as he did not want any sympathy.

'I've told as little people as possible because I don't want people running around feeling sorry for me.....because people would naturally say 'Oh that poor man has cancer'. I don't want people pitying me.' (009)

This attitude was common in the older generation who felt there was a certain stigma associated with having cancer, especially bowel cancer. These individuals worried that the disease implied something bad about the person who had it.

'You get the impression that people look down their nose at you...like you are like a leper.' (059)

Circumstances of sub-optimal support

Respondents spoke of circumstances where they felt they needed more social support. This was usually on completion of a treatment (surgery or chemotherapy). During treatment, they felt they received adequate levels of support.

On the ward, post surgery, many indicated they needed more emotional support from medical staff.

'No I think it's because they just deal with the surgery aspect. They don't deal with it as being cancer.' (008)

A number of individuals experienced a void in informational support between their surgery and attending the cancer centre to discuss chemotherapy. This appeared to heighten anxiety levels. There was a lack of continuity between surgery and chemotherapy.

'Everybody in the (hospital A) says well we don't know anything about this, it's nothing to do with us. So you didn't know anything. If you did, if there was somebody there or you could go somewhere that they could quickly tell you because whenever I went to the (hospital B), they could tell you in 5 minutes basically what is going to happen. If you only could have that sooner it would help matters.' (021)

One subgroup of participants who were under the care of one consultant met a specialist nurse after surgery. The same pre chemotherapy anxiety was not as apparent in their narratives as those who did not receive the same level of support.

The participants appeared to experience optimal support during chemotherapy. The narratives implied that they received adequate support from the medical profession through their attendance for chemotherapy. In addition they described receiving sufficient support from friends and family.

On completion of chemotherapy many participants described a number of physical and psychological difficulties that were not addressed by HCPs. It appears that patients experienced unsatisfactory PCC and indicated a need for further support at this stage.

'Yes there does need to be somebody there to catch you at the end of it all, at the end of the chemo and your visits to the hospital because.....everybody has gone and left you.' (051)

Some individuals who had surgery but did not need chemotherapy treatment seemed to find the time after their surgery challenging. After surgery these individuals described how they were discharged from hospital effectively 'cured'. They reported how they still had to deal with the uncertainty that they had had cancer and that it may return. They worried about persistent bowel problems, felt isolated and experienced a lack of information on how long their expected recovery period should be. They obtained information from their General Practitioner (GP), but they explained that as their GP was not a 'cancer specialist' they did not have as much confidence in them as they would have had in an oncology consultant.

Discussion

Information

The findings highlight the complexity of delivering what would be deemed as successful PCC by all patients. Information need is very personal to the individual and therefore it cannot be assumed that everyone wants to know everything (15). It may be of benefit for HCPs to determine at the initial consultation what type of information seeker an individual is or where they sit on the continuum between active and passive information seeking. However, there has to be an ongoing assessment as patients' approach may change and their need for information increase or reduce. There is not a 'one size fits all' approach to information giving.

The dichotomy presented in the findings is corroborated by recent literature. It has frequently been reported that individuals with CRC are divided between those who want significant amounts of information and those who want minimal information (12, 15-17). A sub group was identified within the 'passive recipients'. These individuals appeared to avoid information on certain aspects of their treatment. They have been classified as 'guarded information seekers' (12). It could be the case that those individuals who desired significant information achieved some degree of control over their treatment. Being diagnosed with a life threatening disease such as cancer could lead to a sense of disempowerment. It is therefore important for HCPs to encourage these individuals to seek out information, to help these patients achieve some degree of control. It is possible that the participants who did not have the same desire for information coped by not facing the reality of their condition. This may led them to not coming to terms with their illness. Alternatively, it may allow them to accept

their diagnosis more slowly, at a pace that they can cope with. It is therefore vital that individuals with CRC receive information that is individually tailored to their own needs.

Participants frequently reported that they had received minimal information on diet. Dietary advice has recently been highlighted as a topic with the highest rank in terms of importance of information needed since bowel surgery (18). Other individuals with CRC reported receiving conflicting advice on diet (19). This is an area that needs addressing, particularly given the nature of the disease.

The present study highlighted two time-points where information was lacking: immediately after surgery before chemotherapy and on completion of chemotherapy. Previous studies have reported these two time-points as periods of anxiety for individuals with CRC as a result of minimal information and/or support (16,20-22). A number of participants appeared to assume incorrectly that their treatment was complete after surgery. This information gap between surgery and attending the cancer centre is something that needs improved, as it was evident that some individuals misinterpreted the situation regarding their treatment.

The participants described a need for more information on follow up appointments and scans. This seemed to be a frequent source of distress and of vital importance, especially as the scans could reduce anxiety levels by addressing the uncertainty surrounding cancer recurrence. The Institute of Medicine (IOM) published a report on cancer survivorship in 2005 (23). This recommended that after cancer treatment, individuals should be given a Survivorship Care Plan (SCP). This plan should detail diagnosis, treatment, potential complications and information on follow-up. This plan could reduce distress by providing more structured care as survivors are aware of when they should be having scans or appointments. It has been argued that SCP could be difficult and expensive to implement and that the information could be easily provided in generic information leaflets similar to those already used at the diagnosis and treatment stage (24). It is unlikely that generic material would be of use to the current study participants as individualized follow-up plans would provide them with the confidence they need that they are being monitored and followed up.

Support

It has been reported that accessing social support is a common form of coping for individuals with CRC (25). Consistent with previously published research, the study participants accessed support from a number of sources (16,19,21,26). There were instances where the participants implied that they did not want support from family and friends. This finding has also been reported by Dunn and colleagues (16). This current research corroborates this finding and underscores its importance, particularly in relation to PCC; HCPs should not presume that patients have or want the support of their family and friends.

As previously stated the period between surgery and chemotherapy and the time after chemotherapy was particularly difficult for the participants. Many desired more support at this stage. Rather than a sudden removal of support at the end of chemotherapy, a gradual decrease in support may prove more beneficial. Those individuals who only had surgery also experienced a lack of support. This desire for long term support has been reflected in the literature (20). Support from a specialist nurse for the period between surgery and chemotherapy and after chemotherapy could prove valuable, particularly as the subgroup of participants who did receive support from a specialist nurse did not suffer the same stress and anxiety before chemotherapy as those who did not receive such support. The benefits of a specialist nurse in CRC have been highlighted. Individuals with CRC have stated that they considered the specialist nurse their main source of support (27) and individuals with CRC who were not seen by the specialist nurse experienced feelings of isolation (15).

PCC

One of the challenges to PCC as highlighted previously was that it strengthens the position of the doctor as the 'expert' (6). All respondents within this study identified and valued the input of an 'expert'. This may not be the case in other illnesses, but in the case of cancer, what is often deemed as a life threatening condition, it appeared important to the patients to have expert input.

Recommendations for practice

Information

- ❖ Information should be individually tailored to individual need. Those who want information want it from who they deem to be the 'expert' for the particular concern.

- ❖ Information should be offered in a variety of formats.
- ❖ Timing
 - Individuals with CRC should be provided with the opportunity to meet with a specialist nurse at an earlier date to discuss options for stoma placement.
 - Relevant information on chemotherapy should be provided as soon as possible post surgery.
- ❖ Patients should be encouraged to speak to other individuals with CRC, as they can be excellent sources of information.
- ❖ More information and advice should be provided on diet.
- ❖ Post chemotherapy, individuals with CRC should be provided with more information on follow-up. Each patient should be provided with a written schedule of approximate dates.

Support

- ❖ There is a need for a specialist nurse to provide more support and information to patients at times of distress (after surgery, pre and post chemotherapy).
- ❖ HCPs should recognise that those individuals without a stoma and therefore without the support of a stoma nurse may feel isolated and require more support at home.
- ❖ HCPs should be aware of individuals who do not require chemotherapy, and may need more 'specialist' oncological support.

Figure 1 summarises the six components of PCC as listed by the IOM linked with 'real life' examples for the experience of individuals with CRC. The findings indicate that a specialist nurse could prove vital for facilitating the achievement of PCC in individuals with CRC. They could provide the necessary information and support at all stages of the cancer care continuum and arrange referrals to other 'experts' for specific concerns.

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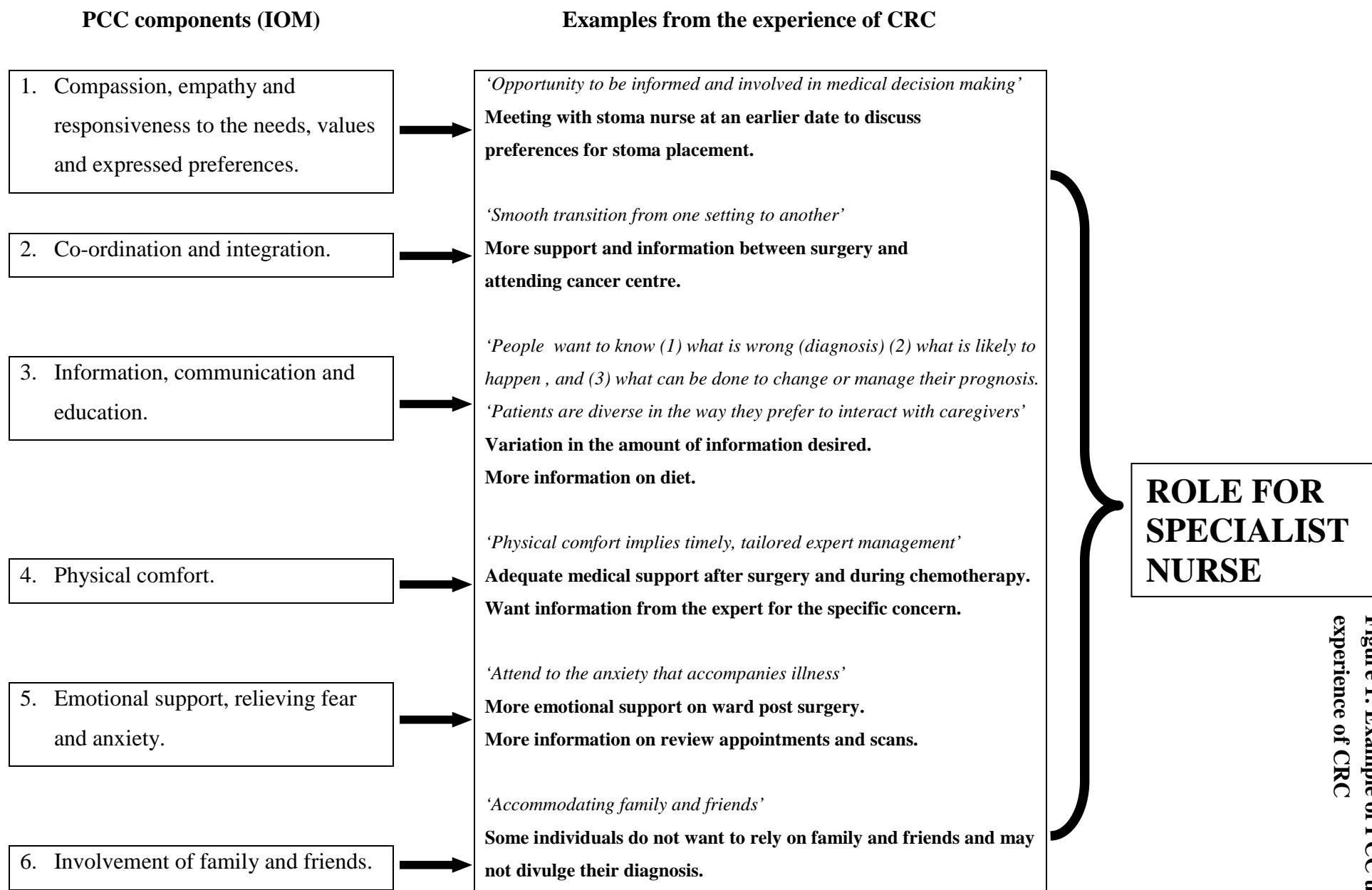


Figure 1: Example of PCC using the experience of CRC